

A look at the family of the person with Autism Spectrum Disorder: Analysis of recent literature

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ABSTRACT

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by difficulties in communication, social interaction, and restricted and repetitive patterns of behavior and interests. This results in losses in social, occupational, and other activities. Family and school face challenges in the socialization and learning of children with ASD, from the observation of the first symptoms to therapeutic and school interventions. The family is the first socialization environment and plays a fundamental role in the care and development of children with ASD. The school also has a crucial role in socialization and learning, requiring pedagogical adaptations, didactic resources and teacher training to promote school inclusion. The study sought to map the recent literature on the role of family and school in the context of autism, highlighting the need for more research in this area.

Keywords: Autism Spectrum Disorder, Neurodevelopment, Child development.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder, which has been gaining ground with scientific research in areas such as health and education. According to the *American Psychiatric Association* (APA, translated into Portuguese as American Psychiatric Association, 2022) it is a condition that is characterized by difficulty in communication and social interaction, as well as by restricted and repetitive patterns of behavior and interests. Such characteristics result in losses in social, occupational, and other activities (APA, 2022). In childhood, the presence of ASD has been a challenge for the family and the school, especially regarding the inclusive needs of socialization and learning.

As it is a developmental disorder, usually identified in the early years of childhood, family members and/or those responsible for the care of the person with ASD, or even educators, are present in situations ranging from the observation of the first symptoms, through diagnosis and therapeutic interventions, including involvement in school and social activities.

In this way, the family accompanies the development of the person with ASD and can also be considered their first socialization environment, as stated by Mapelli *et al.* (2018). The family is

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responsible for the child's care, meeting their basic needs, aiming to support and promote their development (Mapelli *et al.*, 2018).

The school also plays a very important role in the socialization and learning of children with ASD and needs to be prepared to make pedagogical interventions in the literacy and social development of autistic children in regular education. In other words, it needs to align pedagogical practices with the specific needs of autistic students, supporting them as well as their parents.

The school must pay attention to the adjustments related to the elaboration of pedagogical didactic resources and availability of assistive technologies, hiring the necessary support team, such as professionals from the Specialized Educational Service - AEE and support professionals, when necessary, as well as offering teacher training so that they are well prepared to work with all students, respecting diversity and, at the same time, the specificities of each one, so that school inclusion is promoted, as recommended by public policies for education.

It is, therefore, a great challenge for families and schools to experience and experience different situations related to the care and development of people with ASD. This subject has recently gained space in scientific research, but studies on the role of the school and the family of the person with ASD are still very scarce. In this qualitative study, a bibliographic search of articles published in Portuguese, from 2018 to 2023, in the Scielo database, was carried out, with the objective of knowing what has been studied about families in the context of autism, mapping the recent literature.

OBJECTIVE

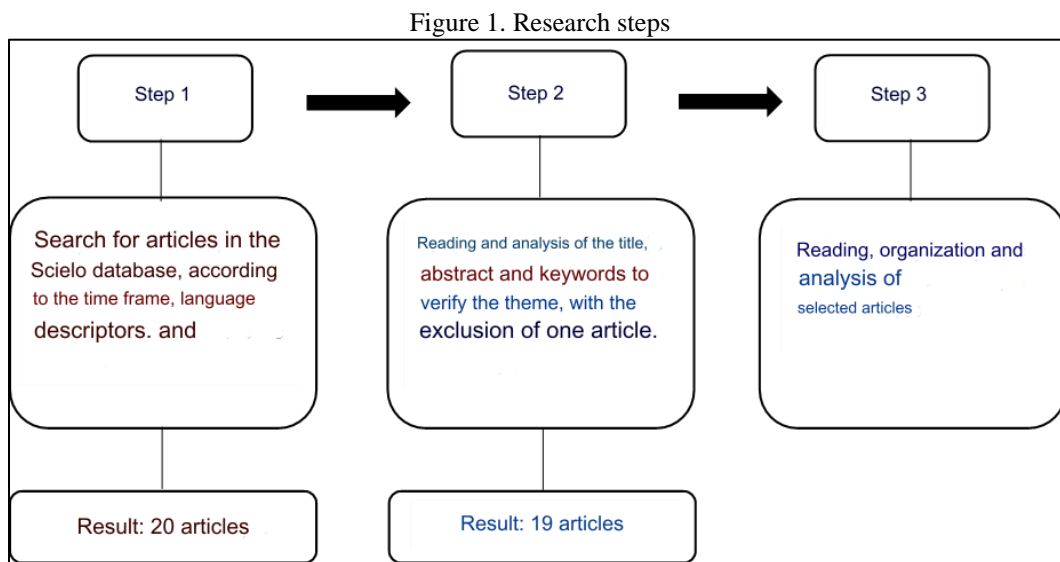
Considering that the involvement of family members and/or guardians is a fundamental part of the care of people with ASD, this research aimed to know what has been studied about families in the context of autism, mapping the recent literature.

METHODOLOGY

This bibliographic research consisted of a descriptive analysis of the literature, published in Brazil between the years 2018 and 2023. For the research, the *Scielo database (Scientific Electronic Library Online)*, translated into Portuguese as *Biblioteca Eletrônica Científica Online* was selected, in the search for articles published in Portuguese, using the descriptors defined by the DECS (Health Sciences Descriptors): "autism", "autism spectrum disorder" and "family", applied in association.

The search took place between December 2023 and January 2024 and was organized in three stages, as shown in Figure 1, starting with the retrieval of 20 articles, using the criteria defined for search, mentioned above. Then, the titles, abstracts and keywords of the articles were read and analyzed, in order to verify the relevance of the theme addressed. One article that did not address the researched theme was

excluded, since it had the child with ASD as the object of research and not his family, resulting in 19 articles. Finally, the articles selected in the research were read, organized, and analyzed, as presented and discussed in the next section.



Source: prepared by the authors, 2024.

DEVELOPMENT

The articles selected in this research were organized in numerical sequence, according to the year of publication, from the most recent to the oldest, in order to facilitate the visualization of their general information, as shown in Chart 1.

Table 1. Presentation of the articles selected in the research

Order	Year of publication	Name of the journal	Field of knowledge
01	2023	Brazilian Journal of Special Education	Education
02	2023	Physis – Journal of Collective Health	Collective Health
03	2022	Latin American Journal of Nursing	Nursing
04	2022	Cogitare Nursing	Nursing
05	2021	Gaucho Journal of Nursing	Nursing
06	2021	Psychology in Study	Psychology
07	2021	CEFAC Magazine	Phonoaudiology
08	2021	CEFAC Magazine	Phonoaudiology
09	2021	Brazilian Notebooks of Occupational Therapy	Occupational therapy
10	2021	Gaucho Journal of Nursing	Nursing
11	2021	Brazilian Journal of Nursing	Nursing
12	2021	Brazilian Journal of Special Education	Education
13	2020	School and Educational Psychology	Psychology
14	2020	Brazilian Journal of Nursing	Nursing
15	2020	Psychology in Study	Psychology
16	2019	School and Educational Psychology	Psychology
17	2019	CODAS Magazine	Phonoaudiology
18	2018	Brazilian Journal of Special Education	Education
19	2018	Anna Nery School Magazine	Nursing

Source: Prepared by the authors, 2024.



Regarding the year of publication, it was possible to observe that research on the family of the person with ASD has been frequent in recent years, with emphasis on the year 2021, which had eight articles published on the subject. In the analysis of the journals, the following major areas of knowledge were identified: Health Sciences, with emphasis on the areas of Nursing, Speech Therapy and Occupational Therapy; and Human Sciences, with the areas of Education and Psychology. The area of Nursing showed the largest number of articles, with seven studies on the theme, followed by Psychology, with four articles, Education and Speech-Language Pathology and Audiology, with three articles each, Occupational Therapy and Collective Health, with one article each. This analysis regarding the area of knowledge indicated that research that investigates the family of the person with ASD has been developed by different areas of knowledge, enabling different approaches and perspectives.

After reading the articles, it was possible to distribute them regarding the theme addressed in three categories for analysis, namely: family performance in the face of ASD; family perceptions of the ASD context; and the family's knowledge about ASD. These categories were defined by the authors, after analyzing the material, taking into account the theme presented by each article; and will be discussed below.

FAMILY'S ROLE IN THE FACE OF ASD

The articles that addressed the family's performance were categorized as such because they investigated the participation of family members in the development of assessments, therapies and other activities carried out with the person with ASD. In this category, the selected articles addressed the family's intervention in the development of social and communication skills and the family's role in the school.

Moares, Bialer, and Lerner (2021) investigated families' initiatives to encourage the growth and development of children with ASD. Similarly, Morato, Pereira, and Silva (2023) observed that the family plays an important role in the child's development when it actively participates in therapeutic interventions. In the research by Freitas *et al.* (2021), it was found that parents act positively when they provide adequate information about the development of their children with ASD, collaborating with professionals who work in therapeutic interventions.

The study by Olivatti *et al.* (2021) analyzed the family's engagement in the implementation of a communication test through pictures, showing that family members were able to apply the instrument, getting involved in the activity. Similarly, Oliveira, Shmidt, and Pendeza (2020) evaluated a social-communicative skills intervention between mothers and children, showing a positive effect on the child's behavior and parental empowerment. This parental empowerment contributes to family members feeling confident to deal with the demands of the person with ASD (Oliveira; Shmidt; Pendeza, 2020).



In the study carried out by Balestro and Fernandes (2019), the perception of caregivers regarding the language development of children with ASD was verified, showing that the participation of the caregiver in the interventions contributes to improving communication skills. And, in the study by Correa, Simas and Portes (2018), the goals and action strategies of mothers of children with ASD in relation to socialization skills were analyzed, identifying that these mothers seek to stimulate the autonomy and independence of their children, contributing to the child having sufficient self-improvement in the future.

Cabral, Falcke and Marin (2021) researched the relationship between family and school, aiming at inclusion. The authors showed that communication between family members and school professionals is important for the learning and socialization of children with ASD. In the study by Menotti, Domeniconi and Benitez (2019), the involvement of parents in the application of educational games was investigated, in order to contribute to learning, being an ally of the school in the child's development. According to the authors, the performance of the family member during the game was positive for the learning of contents, in addition to providing interaction between parents and children.

The articles indicate that the involvement of family members, both in relation to school and in relation to therapeutic interventions, can bring beneficial results for the development of skills and learning of children with ASD. For this, it is necessary that family members are accompanied by professionals who care for people with ASD, so that they are guided on appropriate conducts and behaviors, reinforcing the skills acquired throughout the therapeutic and educational processes.

FAMILY PERCEPTIONS OF THE ASD CONTEXT

In this category, articles that investigated the perceptions or experiences of family members in the face of ASD were included. The studies by Magalhães *et al.* (2021) and Bonfim *et al.* (2020) investigated the experiences of families in the face of the diagnosis of autism. Magalhães *et al.* (2021) identified feelings of sadness and grief experienced by family members in the face of the diagnosis and the impossibility of cure, in addition to evidencing the search for help and changes in routine. Bonfim *et al.* (2020) highlighted the vulnerability of families, due to the scarcity of a support network when diagnosed with ASD.

Studies were also found regarding the perceptions of families regarding the interpersonal relationships existing in this circle of coexistence. Portes and Vieira (2020) investigated the relationship between fathers and mothers of children with ASD. The authors identified an imbalance of tasks between the couple, generating an overload on the mothers, who were the majority in the responsibility for caring for the child with ASD.

In the same sense, Mapelli *et al.* (2018) showed that the mother plays the role of the main caregiver of the child with ASD, while the father assumes responsibility for the family's financial support.



Another issue investigated by Mapelli *et al.* (2018) was the relationship between siblings, which can generate jealousy on the part of siblings, given the overprotection given to children with ASD. It should be noted that these studies reflect specific family dynamics, so that studies with families with other constitutions and in different social contexts can show different results, such as families with more than one child with ASD, or even families that have the mother as responsible for their support.

Finally, two articles were concerned with investigating the experiences of family members during the COVID-19 pandemic, given the challenging situation that this context represented, both for people with ASD and for their families. Teixeira *et al.* (2022) highlighted that the pandemic has amplified the difficulties experienced by people with ASD and their families, negatively influencing emotional, psychological, behavioral, and social issues, interfering with their quality of life. Similarly, Fernandes *et al.* (2021) pointed out that the difficulties experienced during the pandemic period contributed to greater suffering for caregivers, reinforcing the need for them to also receive attention from health professionals. Another aspect identified in the study by Fernandes *et al.* (2021) was the concern of families regarding the continuity of therapies and the development of their children during the pandemic period. It should be noted that the period crossed by the pandemic was a challenge for the entire population, influencing economic, social, health, and education issues, for example. The suspension of several services at the beginning of the pandemic, keeping only those considered essential, as well as social distancing brought changes in the daily lives of the population, with effects not yet studied or little known.

FAMILY KNOWLEDGE ABOUT ASD

Regarding the category defined as the family's knowledge about ASD, articles that researched how family members find information were included, as well as those that investigated what information was needed to guide families. Adequate guidance to family members is essential for knowledge about ASD and its forms of intervention, thus contributing to the support and development of people with ASD.

In this sense, Weissheimer-Kaufmann *et al.* (2021a) highlight that this informational support can come from health, education, or social service professionals, among others. As a result, much information acquired by family members may be insufficient or even contradictory, so that the professionals responsible for the care of the person with ASD should guide access to information, integrating knowledge and clarifying doubts (Weissheimer-Kaufmann *et al.*, 2021a).

In the study developed by Weissheimer-Kaufmann *et al.* (2021b), the following information demands from families were identified: characteristics of ASD, including causes and genetic issues, as well as guidance on the routine, behavior, and rights of people with ASD. The authors concluded that these demands for information should be considered by the professionals involved in the care of people with ASD, in order to support actions and services, supporting the family.



According to Soares *et al.* (2023), other sources of information for family members include social networks, websites of institutions and health teams, enabling a wide dissemination of knowledge and experiences. In addition to the scientific knowledge disseminated, the authors identified that the reports and exchanges of experiences with other families contributed to a greater understanding of ASD.

Finally, in the study by Weissheimer-Kaufmann *et al.* (2022), a digital booklet was prepared and evaluated for families, in order to contribute to access to adequate and essential information for the care of people with ASD. The authors reinforce that the different professionals responsible for caring for people with ASD should contribute to the availability and sharing of information with the family.

The results indicate that guidance to family members is necessary so that there is adequate information about ASD and its forms of intervention and care. In addition, knowledge on the subject enables access to services and rights, as well as contributes to the reduction of stigma and consequent prejudice related to ASD.

FINAL CONSIDERATIONS

Studies on ASD have aroused the interest of different researchers, in different areas, with the possibility of expanding investigations on the subject, addressing different aspects related to it. This study was concerned with knowing what has been investigated in relation to the family of the person with ASD, in order to map the recent literature on the subject.

To this end, a bibliographic search was carried out in the *Scielo database*, in the search for articles published in Portuguese, in the period from 2018 to 2023. The descriptors "autism", "autism spectrum disorder" and "family" were used, resulting in 19 selected articles. The articles were organized according to the areas of knowledge of the journals in which they were published, and the following areas were identified: Nursing, Speech Therapy, Occupational Therapy, Education and Psychology. The different areas of knowledge allow for different approaches and perspectives, expanding information on the subject.

The articles were also organized according to the theme addressed, resulting in three categories: family performance in the face of ASD; family perceptions of the ASD context; and the family's knowledge about ASD.

Regarding the family's performance, it was found that the involvement of family members in different activities can be positive for the development of skills, as well as for the learning of children with ASD. Among the family's perceptions of ASD, it was possible to verify the feelings experienced at the diagnosis, as well as the family dynamics in the follow-up of the person with ASD and the family's routine during the COVID-19 pandemic. In relation to the family's knowledge about ASD, it was possible to observe that guidance to family members is fundamental, enabling adequate information about autism and



its forms of intervention, providing the necessary tools to contribute to the development of the person with ASD.

Other studies on the subject can be carried out, including different databases, allowing for a broader perspective. There is still a lot to be researched about the family and the school in the context of autism, considering that it is a topic that can help for a greater involvement of professionals and family members with the person with ASD, contributing to the development of their skills. Studies on the person with ASD in the school environment should also be deepened, considering that it is necessary to work together with the family, the school and the multiprofessional team, so that the necessary learning and social development is provided to the child with ASD, so that their social inclusion actually occurs.



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